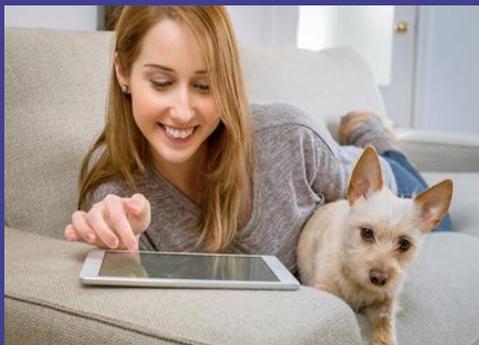


Doeth am Iechyd
Cymru
HealthWise
Wales



A qualitative investigation of participants' experiences of engaging with the HealthWise Wales initiative

Executive Summary



Background and Introduction

- 1.1 Cardiff University commissioned an independent research agency, Opinion Research Services (ORS), to carry out four focus groups with HealthWise Wales (HWW) participants to provide insight into what motivates and prevents participants in continuing to engage in a longitudinal research study, and suggestions of activities HWW could implement to achieve better retention.

Experiences of being an HWW participant so far

Aspects that participants have enjoyed

- 1.2 Overall, participants were very positive about being an HWW participant and welcome being given the opportunity to make a contribution to Wales' health care research.
- 1.3 Most have also found the majority of questionnaires to be interesting, but have particularly enjoyed those which are:
 - Based on specific topics (rather than about health in general);
 - Interactive, such as having to do a task or test; and
 - Targeted to their interests, lifestyle and health.
- 1.4 Moreover, when participants were asked to think about three health-related research topics which they would you be most interested in taking part in a questionnaire about, the most popular were: mental health; cancer; dementia and diet & exercise.
- 1.5 Participants also enjoy the flexibility of being able to fill in questionnaires in their own time: questionnaires are often completed during commutes to and from work, at home in the evenings and during lunch breaks.

Aspects that participants have *not* enjoyed

- 1.6 However, there are some aspects of the programme that participants do not think have worked so well or need improving, such as:
 - Knowing how to report technical issues;
 - Not understanding how certain topics or questions relate to health due to lack of background information (for example, a recent questionnaire about lead);
 - Some of the more general, longitudinal questionnaires are repetitive and boring;
 - Sometimes being sent questionnaires which are not relevant to them (for example, on the topic of maternity when they do not have children);
 - Important questions are sometimes missing and nowhere for participants to record key contextual information;
 - The range of response options do always offer enough choice to convey participants' views and feelings;

Certain health topics causing anxiety, upset and concern (for example, questionnaires about cancer and dementia; and

The lack of regular communication in terms of general emails inviting participants to complete questionnaires and not hearing back about the results or consequences of the research.

Motivators and barriers of taking part in questionnaires regularly

- ^{1.7} Participants were asked to think about and discuss the main motivators and barriers (for themselves, and others more generally) in taking part in HWW questionnaires on a regular basis, which are summarised in the table below.

Motivators	Barriers
Wanting to help and 'give back' to the NHS	Technical issues and uncertainty around how to report links not working or questionnaires failing to load
Being proactive and taking responsibility of one's own health	Not meeting the selection criteria
Feeling represented and having your voice heard	Some of the questionnaire topics can be frightening and cause health anxiety
Helping to drive change & being involved in something important	Concern that there is not enough funding to make improvements to health service
Supporting specific health research into areas of personal interest	Trying to find which questionnaires need to be completed can be difficult (and involves scrolling past already completed surveys)
Enjoy filling in questionnaires	The initial number of surveys available at sign up can be overwhelming
Being genuinely interested in research & health-related topics	Some questionnaire topics are quite personal and may be considered an invasion of privacy
Opportunities to learn about research & health	Lack of background information and context around specific research topics/ questionnaires
The online aspect: quick, easy, can be done in your own time & feels more 'confidential' than telephone or face-to-face methodologies	Some people do not have access to the internet or have poor signal in their area (e.g. rural areas in Wales)
Being part of HWW provides an increased sense of community & connection to being Welsh	Lack of time to spend on filling in questionnaires

Improving HWW research retention

Improving to the ‘user experience’ to increase retention

- 1.8 The groups were subsequently asked to think about how HWW could encourage more of its participants to complete questionnaires more regularly. Suggestions included:

A mechanism whereby participants can easily report technical issues;

An explanation about the nature of longitudinal research, and why this often involves ‘repetitive’ surveys and a lack of feedback on ‘hard results’;

A link to further information for anyone who is concerned about their health after filling in a questionnaire;

Staggering the number of questionnaires, so that new participants are not bombarded, and longer-term participants receive more regular invitations to take part in research;

Sending out reminders;

Making it clear when specific questionnaires will close;

An estimated time of how long each questionnaire will take;

Making participants’ accounts more user-friendly so that they can easily see which questionnaires are available to complete when the log in;

Freetext boxes at the end of the questionnaires where participants can add any information they think is important, as well as give feedback about their experience of completing it;

A tick box at the beginning of each questionnaire to give participants the opportunity to opt out of the questionnaire (and the reason why).

Feedback on results and how HWW research has made a difference

- 1.9 Participants would like to receive more feedback about how questionnaire data has been used. Although the majority accepted it is not always possible to receive ‘hard results’ due to the longitudinal nature of research, it was still felt that HWW should attempt to send participants some topline feedback, such as:

How they compare to others and fit in the with rest of the results;

Feedback about any health behaviours they could improve based on the data they provide;

Being able to see how many people have completed the questionnaires, broken down by demographic;

Being able to access their own data to look at trend changes in their own views and behaviours;

Infographics to as a way of giving feedback and providing a visual representation of information; and

Updates or information around what is hoped to happen as a result of the research, or prospective future research.

Increasing awareness that of what is available via the HWW website

- 1.10 There was a lack of awareness that participants can log into the HWW website and look for questionnaires available for completion, rather than waiting to be emailed about it. It was agreed that HWW could do more to prompt participants to regularly check the website.

The provision of workshops, events and panels

- 1.11 It was felt that workshops, where participants can meet each other face to face and provide feedback to HWW would also increase the sense of being part of a wider community, which would hopefully increase buy-in to regular participation and spread the word about HWW.
- 1.12 Indeed, everyone agreed that the current workshop had been a useful form of engagement, and that that they would be interested in attending similar events in the future. It was also suggested that HWW holds events about specific health-related topics (for example, mental health) which it could invite participants too.
- 1.13 Furthermore, nearly everyone expressed interest in being part of HWW's user panel and would welcome the opportunity to be more involved in delivering the programme.

Increasing retention for harder to reach groups (males, younger people and those from lower socio-demographic areas)

Offering a more inclusive service beyond online communication, such as increasing presence in local communities

- 1.14 Although participants among the four groups were happy to take part in HWW online, it was acknowledged that others who have signed up may struggle with this form of communication. Indeed, it was reasoned that if HWW are keen for a broader demographic of people, it should offer telephone, paper, Skype or face-to-face contact for those who try to fill questionnaire in online but encounter difficulties (for example, due to not understanding the questions; lacking confidence in using the technology; or struggling with signal or having access to a device) – even though it will cost more to provide these additional services. It was felt that doing so would particularly help with encouraging those from more deprived, rural communities.
- 1.15 The consensus was that HWW also needs to undertake more engagement and awareness raising in communities in order to increase retention among younger people, males and people living in lower socioeconomic areas. Specifically, it was reasoned that working with local groups, charities, businesses and events will increase buy-in from demographics who are currently '*slipping between the gaps*'. Indeed, it was suggested that HWW should reach out to an collaborate with schools, universities, colleges, leisure centres and sports clubs in order to promote the importance of regularly engaging with HWW research.

Providing monetary incentives

- 1.16 Participants felt torn about offering monetary incentives to try to boost retention. It was felt that this would help encourage those who are younger or are from a lower socio-economic status to part in more questionnaires, but there was concern that people may only fill them in for the money rather than taking the time to consider they are providing. Furthermore, others would prefer money to be spent on research or health services, rather than incentivising participants.
- 1.17 However, there was some open-mindedness possible ‘happy mediums’, such as entering participants into a one-off prize draw once they have completed a certain number of questionnaires or offering some sort of loyalty scheme which does not involve receiving money for completing questionnaires on a regular basis.
- 1.18 Others felt that from their point of view, a simple ‘thank you’ or badge for reaching certain targets would go a long way in making them feel valued and part of something important.

Targeting research based on individuals’ interests and demographics

- 1.19 Although participants among the groups mainly find the research interesting, it was argued that some may struggle to relate to the topics covered in the questionnaires – and tailoring research to participants’ ages, backgrounds and interests would increase interest and buy-in from all three ‘hard to reach groups.’
- 1.20 During a poster design task, it was also suggested that HWW could better target its advertising campaigns so that there are more inclusive to harder to reach groups. For example: making to clear that illnesses do not discriminate; including a more diverse pool of people in adverts, such as young people and men, and advertising specifically targeted to men, such ‘males and mental health.’ Indeed, it was stressed that participants need to feel represented and able to identify with the research they see advertised.

Using art-based workshops and other creative techniques

- 1.21 Similarly to the idea of incentivizing participants, views on HWW undertaking arts or performance-based’ workshops in the future were mixed. However, a reasonable proportion felt that communicating with younger people using poster-making, ‘storytelling’, making videos, music and other animations could be a useful tool, while others thought that these activities could also be attractive to participants more generally.
- 1.22 Participants also acknowledged that thinking of more creative ways to engage with younger people is important, but suggested that this could be done through local sports groups or events rather than arts-based activities because it is a ‘better fit’ for the community and more likely to have a stronger influence.

An HWW APP and social media

- 1.23 It was also suggested that HWW could develop an APP where participants can access questionnaires, quick opinion polls and receive updates about health and social care research. It was felt hat this would be useful generally, but particularly with engaging young people

1.24 Participants also suggested that HWW could use social media platforms to undertake more targeted campaigns for young people – although a few younger participants were unsure about whether they would be likely to engage with the programme in this way.

Improving retention through digital engagement

1.25 The vast majority of participants across the four groups did not know that HWW has Facebook, Twitter and Instagram accounts and no one could recall having seen any recent campaigns via social media. A reasonable proportion of the groups said they would be interested in following HWW on social media now that they know about it, although some expressed less interest in engaging with HWW in this way and did not consider it an appropriate platform for the programme.

1.26 Despite the mixed views towards social media, it was suggested that HWW could do more to engage with participants and increase buy-in via this platform, such as:

Creating an online community where information about research and different topics can be shared and discussed;

Inviting participants to take part in quick, non-invasive opinion polls (although there was less interest in taking part via in these type of short surveys via text).

1.27 Moreover, participants would personally be drawn to digital campaigns which are: visual, emotion-evoking, but also fun. They should also include: short and ‘snappy’ sentences; infographics to present facts and figures; a focus on the ‘Welsh perspective’ of HWW; and possible celebrity endorsements. It was argued that increasing participants’ sense of responsibility and making them believe that that they really can make a difference would be extremely powerful. This was felt to be particularly important when designing campaigns for the harder to reach groups.